DOCUMENT RESUME

ED 179 047 EC 122 020

AUTHOR Ross, E. Clarke
TITLE The Federal Government's Deinstitutionalization Program Initiatives: A Status Report (A Litany of Reports, Studies, Recommendations, Policy Debates, and Even Some Progress).
INSTITUTION United Cerebral Palsy Associations, Inc., Washington, D.C.
PUB DATE May 79
NOTE 21p.
JOURNAL CIT Word from Washington Analysis; v8 n3 May 1979

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Federal Aid; *Federal Government; *Federal Programs; *Handicapped; Handicapped Children; Health Insurance; Health Services; *Public Policy
IDENTIFIERS *Deinstitutionalization (Handicapped)

ABSTRACT

Analysis of six federal government studies on deinstitutionalization is followed by a discussion of initiatives enacted by the 95th Congress and proposals under consideration in the 96th. Among studies described are reports by the U.S. Government Accounting Office ("Returning the Mentally Disabled to the Community: Government Needs to Do More"); Congressional Budget Office ("Long Term Care for the Elderly and Disabled"); President's Commission on Mental Health; National Institute for Mental Health ("Comprehensive Community Support Systems Demonstration Program"); Department of Health, Education, and Welfare Task Force on Deinstitutionalization; and the White House Conference on Handicapped Individuals. Among the initiatives of the 95th Congress cited are The Developmental Disabilities Amendments, congregate housing services, and use of resources from the Department of Housing and Urban Development. Proposals before the 96th Congress are said to include social services support, National Health Insurance, and work incentives under Supplemental Security Income and Disability Insurance. Also considered are issues in funding small group residences as Intermediate Care Facilities and a health care support proposal put forth by the National Association of Retarded Citizens and the Paralyzed Veterans of America. (CI)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

Word from Washington

Analysis

ED179047

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

Volume Eight

Number Three

THE FEDERAL GOVERNMENT'S DEINSTITUTIONALIZATION PROGRAM INITIATIVES: A STATUS REPORT (A LITANY OF REPORTS, STUDIES, RECOMMENDATIONS, POLICY DEBATES, AND EVEN SOME PROGRESS)

E. Clarke Ross
Director
Governmental
Activities
Office

United
Cerebral
Palsy
Associations
Inc.

Chester
Arthur
Building
425 I Street
Northwest
Suite 141
Washington,
D.C. 20001

(202) 638-6169

EC122020

In Depth Resource Material
Prepared For Affiliates Of
United Cerebral Palsy Associations, Inc.

BY

E. Clarke Ross
Director
UCPA Governmental Activities Office

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
E. Clarke Ross

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

May, 1979

CONTENTS

INTRODUCTION 1

A LITANY OF REPORTS, STUDIES, AND RECOMMENDATIONS 1

- U.S. Government Accounting Office. Returning The Mentally Disabled To The Community: Government Needs To Do More. 1977 1
- U.S. Congressional Budget Office. Long-Term Care For The Elderly And Disabled. 1977 3
- President's Commission On Mental Health. Interim Report. 1977 5
- National Institute For Mental Health. "Comprehensive Community Support Systems Demonstration Program." 1977 5
- Department of Health, Education, and Welfare Task Force On Deinstitutionalization, 1977-1978 5
- White House Conference On Handicapped Individuals. Implementation Report. 1978 6

95TH CONGRESS INITIATIVES. 7

- Overview 7
- The Developmental Disabilities Amendments 7
- Comprehensive Services For Independent Living 8
- Congregate Housing Services 8
- Comprehensive Long-Term Care 9

UTILIZING HUD RESOURCES 9

- Overview 9
- The Section 202 Construction Experience 10
- Combining HUD And HEW Resources 11

PROPOSALS BEFORE THE 96TH CONGRESS 11

- Work Incentives Under SSI and DI 11
- Social Services Support 12
- National Health Insurance Proposals 12
- A Word On Appropriations 13

ADVANTAGES AND DISADVANTAGES OF ICF/MR FUNDING FOR SMALL GROUP RESIDENCES 13

- Overview 13
- Advantages 14
- Disadvantages 14

NARC/PVA FEDERALIZED HEALTH CARE SUPPORT PROPOSAL 14

- Problems Being Addressed 15
- A New Modified Medicare Benefit For Persons With Long-Term Disabilities 16

CONCLUSION 17

INTRODUCTION

This paper was initially conceptualized as the text of a speech on the "Role Of The Federal Government And Funding Programs Relative To Deinstitutionalization" prepared for a statewide conference sponsored by the Virginia Department of Mental Health and Mental Retardation and Mental Health Services of the Roanoke Valley.

As research proceeded, as its scope expanded, and as discussions with UCPA affiliate representatives occurred, the recommendation was made repeatedly that the subject was appropriate for a Word From Washington Analysis paper.

Unlike previous Analysis papers prepared by the UCPA Governmental Activities Office since 1972, this paper does not contain introductory explanations describing the nature and scope of federal programs. It is assumed that readers are already familiar in general with Medicaid, Supplemental Security Income, Section 8 rent subsidies, Developmental Disabilities, and the other federal programs UCPA affiliates have come to know and utilize.

This paper reviews federal government studies on deinstitutionalization, outlines important initiatives enacted by the 95th Congress, and discusses proposals being considered by the 96th Congress. The UCPA governmental activities office requests the advice and recommendations of UCPA affiliates regarding the 96th Congress proposals. This paper is not only intended to convey information regarding the activities and status of federal deinstitutionalization efforts but also to foster further communication within UCPA about 96th Congress proposals.

A LITANY OF REPORTS, STUDIES, AND RECOMMENDATIONS

To fully understand the history and environment behind proposals being considered by the 96th Congress, it is appropriate to briefly review the major federal government reports and studies on various aspects associated with deinstitutionalization.

U.S. Government Accounting Office. Returning The Mentally Disabled To The Community: Government Needs To Do More. January 7, 1977.

This comprehensive study provides an excellent introduction to understanding the federal government's deinstitutionalization efforts. The study accepts the popular understanding of deinstitutionalization as involving the prevention of unnecessary admission and retention, the development of appropriate alternatives in the community, and the improvement of institutional care.

The study identified 11 major departments and agencies and 135 programs with an impact on the mentally disabled (includes the developmentally disabled for purposes of the study) and concluded that many persons have been released from institutions before sufficient community facilities and services were available and without adequate planning and follow-up. Many other persons enter, remain in, or reenter institutions unnecessarily.

- The Subject Of Cost

The GAO study concluded:

> "We did not compare the cost of institutional care with community-based care. The goal of deinstitutionalization was mandated by the executive, legislative, and judicial branches of the government because community-based care was believed to be more humane and because people have a legal right to live in the least restrictive environment consistent with their needs. The relative costs of the two types of care were not specified as criteria for determining the more desirable."

- No National Plan

The GAO further concluded:

> "Although deinstitutionalization of the mentally disabled has been a national goal since 1963, federal agencies that can influence this goal have not yet developed a comprehensive and clearly defined national plan to achieve the goal. They have not developed a management system to insure that the goal is properly implemented and, for the most part, made no concerted efforts to accomplish the deinstitutionalization objective."

- GAO Recommendations To Congress

Recommendations made to the Congress included:

> (1) Establish a committee in each chamber with overall responsibility to oversee all federal efforts toward deinstitutionalization;
>
> (2) Establish legislative links among federally supported programs so that they are mutually supportive in accomplishing deinstitutionalization;
>
> (3) Require State Developmental Disabilities programs to focus on coordination and case management;
>
> (4) Strengthen Developmental Disabilities and Community Mental Health Centers funding; and
>
> (5) Strengthen state formula grants for mental health services.

- GAO Recommendations To The Office For Management And Budget

Recommendations to OMB were to:

> (1) Direct agencies to develop and implement independent objectives and plans to accomplish deinstitutionalization;

(2) Clearly identify roles and responsibilities of federal agencies; and

(3) Direct federal regional councils to coordinate and evaluate deinstitutionalization at the regional level.

OMB believed these recommendations were unwarranted and would unjustifiably interfere with State and local responsibilities.

The GAO study contained numerous recommendations regarding the 135 programs with an impact on deinstitutionalization.

U.S. Congressional Budget Office. Long-Term Care For The Elderly And Disabled. February, 1977.

The CBO study defined long-term care as health and social services provided to chronically disabled persons. Total demand for such services was estimated to increase from 5.5 to 9.9 million persons in 1975 to 6.3 to 11.1 million persons in 1980. Of these 5.5 to 9.9 million functionally disabled persons, only 1.9 to 2.7 million received long-term care under government programs in 1975. Of importance to UCPA affiliates is the estimate that 1.4 to 4.7 million of these persons are between the ages of 18 and 64.

In 1975, federal, state, and local governments spent $5.7 to $5.8 billion on long-term care; $3.1 billion or 56% of this was federal spending and 77% of this funding was derived from Medicaid.

The CBO report concluded that while many disabled persons receive no long-term care, there is evidence that 20 to 40% of the nursing home population could be served at less intensive levels.

- General Findings

Of particular interest are several findings:

(1) "Perhaps the single largest factor behind the lack of adequate or appropriate long-term care for a large number of the chronically disabled is the general lack of formal alternatives to institutional care."

(2) Government efforts to provide appropriate levels of care have largely failed because of the lack of coordination and the fragmentation of responsibility at the local level which parallels the fragmented responsibility at the federal level. Additionally, there has been a lack of adequate placement criteria and assessment mechanisms.

(3) "Although no conclusive data is available, the weight of evidence appears to support the hypothesis that adequate funding of home care and sheltered living will reduce the rate of growth in the number of persons seeking institutional nursing care. Such changes take place slowly, however, so that only a relatively small reduction in the rate could be expected to occur in the period 1979-1985."

- Possible Future Governmental Directions

The CBO study conceptualizes three alternative future policies in the long-term care area.

(1) Stimulate noninstitutional services under Medicare and Medicaid.

Such a proposal would require home health benefits as a mandatory service. One of the major arguments against this proposal is that the existing federal financing mechanism, while opening up benefits for community care, would continue to promote institutional services.

(2) Establish a long-term care insurance entitlement program.

This proposal envisions institutional care, sheltered living and congregate housing, and home based services. The CBO declares that "demand for long-term care services under an entitlement (insurance) program is potentially very large because the estimated need is great." Thus, satisfaction of demand, which would depend on an increase in the supply of services, would not be fulfilled.

It is interesting to note the CBO projections that "the growth of expenditures for sheltered living facilities will probably be quite rapid compared to projections under present law." Additionally, estimated spending for home health agency services would increase even more rapidly than that projected to occur under option #1 previously cited.

(3) Consolidate current long-term care financing sources and funnel these through a single agency responsible for long-term care.

This proposal would consolidate long-term care benefits under Medicare and Medicaid with Title XX Social Services into a 60% federal matching grant program. States would be required to establish community centers. This option would provide an administrative focus for long-term care, establish a uniform set of services, and eliminate the divisions between health and social services now necessitated by current financing arrangements.

This would not be an entitlement program so the number of people served could be limited by appropriations.

- Comparison Of Existing Programs With CBO Proposals

(in billions)

	1980	1982
Potential Demand	$32-47	$42-60
Existing Federal Programs	$ 7-8	$ 9-10
Home Health Expansion	$ 8-9	$11-14
Entitlement Program	$20-23	$29-36
Long-Term Care Grant Program	$ 8-9	$11-14

The CBO study assumed that there would be little, if any, long-term care benefits in any national health insurance scheme.

President's Commission On Mental Health. Interim Report. September 15, 1977.

The PCMH report reached two conclusions: (1) mental health services cannot be developed in isolation from other human services and (2) greater efforts must be made to remove the stigma from mental illness.

Recommendations were made in four areas: (1) improving the provision of needed mental health services, (2) financing needed mental health services, (3) expanding the base of knowledge about mental illness and mental health, and (4) identifying strategies that may help prevent mental disorders and disabilities.

- PCMH Financing Recommendations

In addition to recommending an interagency group within the federal government to coordinate policies and programs affecting the development of community based care for the mentally disabled. Specific financing recommendations included (1) more funds for the Section 8 rent subsidy program, (2) more funds for Community Mental Health Centers, (3) greater manpower training programs, (4) Health Planning recognition of the mental health field, (5) inclusion of mental health benefits in any national health insurance program, (6) the need for an assessment of the current costs of providing specific mental health services in different settings and organizations, (7) changes in Medicare and Medicaid changes to finance psychiatric inpatient services, and (8) the establishment of a new Intermediate Care Facility (ICF) program for mentally disabled persons.

National Institute For Mental Health "Comprehensive Community Support Systems" Demonstration Program. (Source: HEW News, November 15, 1977).

On November 15, 1977 DHEW's NIMH launched a $3.5 million demonstration program involving 16 states. Alabama, Arizona, Georgia, Massachusetts, New Jersey, Ohio, and Oregon collectively received $1.033 million for strategy development projects to help States plan how best to use their currently available resources. Additionally, California, Colorado, Florida, Mississippi, Minnesota, Missouri, Montana, New Jersey, and Texas collectively received $1.972 million for State and local demonstration and replication projects to help "more advanced" States further develop exemplary local programs as models that might be implemented elsewhere. These projects are to rely on a core service agency as lead agency using the case management approach.

Department of Health, Education, and Welfare Task Force On Deinstitutionalization, 1977-1979.

Also on November 15, 1977 DHEW Secretary Joseph Califano established a Department-wide task force on deinstitutionalization of the mentally ill and mentally retarded (to include the developmentally disabled) to review HEW policy which affects these groups. The task force was staffed by the Office of Social Services/ Human Development in the Office of the Assistant Secretary for Planning and Evaluation.

• A Community Based Care Proposal

The DHEW Task Force has proposed a January 12, 1978 option to promote community-based care of the mentally disabled. The option proposal is based on the following assumptions:

> "Medicaid (Title XIX), by virtue of open-ended funding and an average federal match of 56.8%, provides to States a strong incentive toward institutional care of the impoverished chronically ill and disabled. Historically, Medicaid was meant to pay for the care of medical indigents and, as such, cannot be faulted for the medical model that it encompasses. But more powerful than the medical model of care and treatment is its open-ended budget - an irresistable attraction for the States, service providers, and client groups alike. Thus, we have witnessed ballooning growth of the Medicaid budget, accompanied by constant pleas for increased coverage of population and services and for more flexible standards."

The option proposal attempts to limit institutional care while promoting community alternatives. Such an approach would cap the Medicaid budget, increase the Life Safety Code standard requirement, reduce the federal matching rate for institutional services, and increase the federal matching rate for community service programs, specifically for Title XX Social Services, Vocational Rehabilitation, Developmental Disabilities, and Community Mental Health Centers. The proposal utilizes federal matching rates as national policy preferences.

The DHEW task force submitted a December, 1978 decision memo to Secretary Califano which has received no action to date. The memo recommendations will be reviewed by reporting the Administration's positions on pending 96th Congress legislation.

White House Conference On Handicapped Individuals. Implementation Report. December, 1978.

The White House Conference On Handicapped Individuals passed 810 recommendations and 142 resolutions. From all these items, ten priority action proposals were selected. Some of these 10 items were the need to formulate a national policy on disability, recognition of the unique needs of individuals with disabilities, consumer involvement in planning and decision making, establishment of a National Clearinghouse Information System, identification of a single compliance/enforcement unit for civil rights, removal of disincentives to work in existing programs, the development of a continuum of basic education, career training, and adult education opportunities, and the need for more data.

A ninth proposal is the establishment of a Federal Programs Coordinating Center with firm statutory authority and adequate funding to coordinate all federal programs and expenditures on behalf of individuals with disabilities. Such a center would have approval authority for fiscal and personnel allocations, ability to conduct needs assessments and evaluations, opportunity to develop program objectives and standards, and include the National Council on the Handicapped and a Presidential advisor designated as the White House specialist for the handicapped.

The final recommendation is for the enactment of a comprehensive national health insurance program which would include the following provisions:

- Medical care for persons who cannot obtain medical insurance because of pre-existing conditions;
- Preventive medicine coverage to prevent disability and exacerbation of disability;
- Employment without fear of losing health coverage;
- Provision of home based care and support services such as attendant services and prescription medicine and supplies; and
- Emphasis on long-term care and assisted living arrangements.

95TH CONGRESS INITIATIVES

- Overview

The 95th Congress (1977-1978) enacted several laws with substantial potential for fostering deinstitutionalization activities. Among the more substantial of these laws are: (1) P.L. 95-478, "Comprehensive Older Americans Act Amendments of 1978," October 18, 1978; (2) P.L. 95-524, "Comprehensive Employment And Training Act Amendments of 1978," October 27, 1978; (3) P.L. 95-557, "Housing And Community Development Amendments of 1978," October 31, 1978; and (4) P.L. 95-602, "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978," November 6, 1978.

- The Developmental Disabilities Amendments

P.L. 95-602 amended the Developmental Disabilities Act to require that 65% or $100,000 (whichever is greater) of a state's DD formula grant be allocated to priority service areas defined as case management services, child development services, alternative community living arrangement services, and nonvocational social-developmental services. The state plan must assess and describe the extent and scope of the priority services within the state. Priority service areas are to be examined at least every 3 years.

In going to a national priority area approach (although a waiver authority is also contained) the Congress thus rescinded the P.L. 94-103 requirement that 30% of a state's allotment shall be used "for the purpose of assisting it in developing and implementing plans designed to eliminate inappropriate placement in institutions of persons with developmental disabilities." Though one could argue the P.L. 95-602 amendments contain a conceptual deemphasis of deinstitutionalization, programmatic realities through the priority approach have the affect of strengthening deinstitutionalization and national accountability/evaluation at the same time.

Tom Stripling of the Federal Programs Information and Assistance Project maintains that answers to four general questions presents a global conceptualization behind the DD program as amended by P.L. 95-602:

(1) Who is to be Served?
Persons with developmental disabilities whose needs cannot be otherwise met under other federally-assisted programs.

(2) What is to be Done?
Specialized and comprehensive services will be coordinated, monitored, and evaluated.

(3) How is This to be Achieved?
Through comprehensive planning, interdisciplinary training, and innovative habilitation techniques.

(4) What are to be the Major Considerations in This Process?
Protecting the legal and human rights of persons served, reducing the need for institutional care, and helping clients achieve their maximum potential.

(Source: Stripling, Tom and Hamilton, Regina. The Developmental Disabilities Program. Washington, D.C.: FPIAP, February, 1979 Draft).

• Comprehensive Services For Independent Living

P.L. 95-602 established a new title of the Rehabilitation Act, Title VII, entitled "Comprehensive Services For Independent Living" to provide independent living services to meet the needs of individuals "whose disabilities are so severe that they do not presently have the potential for employment but may benefit from Vocational Rehabilitation services which will enable them to live and function independently."

Eligible persons are those "whose ability to engage or continue in employment, or whose ability to function independently in his family or community, is so limited by the severity of his disability that vocational or comprehensive rehabilitation services appreciably more costly and of appreciably greater duration" than VR services are required. Priority is given to persons now unserved by the VR or DD Acts.

Each state is to receive a minimum allotment of at least $200,000 on a 90% federal match basis. At least 20% of the funds allocated to the states must be granted to public agencies and private nonprofit organizations and "handicapped individuals shall have a substantial role in developing the State plan." From the state grants, states are to establish centers for independent living, independent living services for older blind individuals, and they may establish protection and advocacy programs. Authorization levels are $80 million in 1979, $150 million in 1980, $200 million in 1981, and such sums as may be necessary in 1982.

• Congregate Housing Services

Title IV of P.L. 95-557 established the "Congregate Housing Services Act of 1978." HUD contracts of not less than 3 years or more than 5 years (which are renewable) are authorized to finance congregate housing services programs by public housing agencies or Section 202 nonprofit sponsors for the elderly or nonelderly handicapped.

Congregate services programs include "personal assistance" and "nutritional meals" to eligible residents "who, with assistance, can remain independent and avoid unnecessary institutionalization." All recipient housing projects must provide "full meal service adequate to meet nutritional needs." Personal assistance may include, but is not limited to, "grooming, dressing, and other activities which maintain personal appearance and hygiene." Housekeeping and other services essential for maintaining independent living may be financed. Service plans must be developed by housing sponsors in consultation with appropriate local social service agencies to determine the most appropriate means of providing services and identifying alternative available sources of funding such services.

No service provided under this new authority may be treated as income to the resident. And, "individuals receiving services assistance under this title shall be deemed to be residents of their own households, and not be residents of a public institution, for the purpose of any other" federal or State program.

Local and state public service agencies for the handicapped are to review and comment on the applications for congregate housing services. Each applicant must also establish a professional assessment committee to identify residents and design services to meet their needs.

P.L. 95-557 authorizes $20 million for 1979, $25 million for 1980, $35 million for 1981, and $40 million for 1982. P.L. 95-392 appropriates $10 million for 1979.

• Comprehensive Long-Term Care

P.L. 95-478 authorizes the Federal Commissioner on Aging to make grants to selected state aging agencies as well as private nonprofit organizations and other public agencies to develop "comprehensive, coordinated systems of community long-term care for older individuals with special emphasis upon services designed to support alternatives to institutional living."

UTILIZING HUD RESOURCES

• Overview

As recently as five years ago, federal housing agencies played an almost negligible role in financing community housing for non-elderly, handicapped persons. At the time, the only statutory reference to housing for handicapped persons was found in the language of Section 202 of the "Housing Act of 1959," which authorized a direct loan program for constructing housing for the elderly and certain persons with handicaps. In 1973 United Cerebral Palsy Associations, Inc. and the National Association for Retarded Citizens developed a systematic advocacy effort to convine Congress to amend its housing legislation to specifically include persons with disabilities.

Passage of the "Housing and Community Development Act of 1974" (P.L. 93-383) marked an important watershed in federal housing legislation for persons with handicaps. Under this law, both mentally and physically handicapped persons were made eligible for a variety of federal housing assistance programs including the expanded Section 8 rent subsidy program. Immediately

following the enactment of P.L. 93-383, the Consortium Concerned With The Developmentally Disabled (CCDD) established its Task Force On Housing.

The significance of the 1974 and subsequent amendments was not operationalized by the Department of Housing and Urban Development (HUD) until March, 1977 when HUD Secretary Patricia Harris established an Ad Hoc Committee on Independent Living for the Disabled followed in May, 1977 by a new HUD Office of Independent Living for the Disabled. Despite some disappointments, our experience with HUD from March, 1977 to January, 1979 has been extremely positive; HUD's leadership during this period of time has been a significant factor in allowing non-elderly handicapped persons to gain an initial foothold-albeit, still not well established-in the federal housing arena.

• The Section 202 Construction Experience

Section 202 authorizes low interest loans to nonprofit sponsors of housing for the elderly and handicapped. Some CCDD member chapters have been designated as Section 202 sponsors for housing for the disabled as follows:

	1976	1977	1978	Totals
Total Number of Section 202 Projects Specifically For The Disabled	17	24	99	140
Sponsors Associated with the National Association of Private Residential Facilities for the Mentally Retarded	6	3	4	13
Sponsors Associated with the National Association for Retarded Citizens	6	8	25	39
Sponsors Associated with UCPA	3	2	2	7

Thus 42% of the Section 202 loans for the non-elderly handicapped have been awarded to three of the five CCDD Task Force on Housing members.

The late arrival of sponsors for housing for the handicapped and their relative inexperience compared to elderly housing sponsors resulted in F.Y. 1979 and F.Y. 1980 minimum set-asides of $50 million for non-elderly handicapped Section 202 projects (6.2% of $800 million). In F.Y. 1979, HUD actually awarded $67 million in Section 202 loans to non-elderly handicapped sponsors; when the special chronically mentally ill demonstration program is added to these awards, the non-elderly handicapped received $82 million of the $800 million Section 202 loans.

Additionally, the number of Section 202 applicants wishing to sponsor housing for the non-elderly handicapped is growing. Of 1,229 Section 202

applications in 1977, 71 were for the non-elderly handicapped (5%). This proportion dramatically changed in 1978; of 878 Section 202 applications, 178 were for the non-elderly handicapped (22%).

• Combining HUD And HEW Resources

The key to success in operating specialized housing programs for persons with substantial disabilities is the packaging and combining of various funding sources. Programs throughout the nation are combining HUD and HEW funding. An example of this is found in Pittsburgh.

UCPA of the Pittsburgh District operates a supervised apartment program. The residential services director was initially hired under a Regional Office Vocational Rehabilitation grant. All residents are SSI recipients. All residents are Section 8 rent subsidies recipients. All residents receive Title XX Social Services support (for salaries of support staff who reside in another apartment and for transportation). The physical accessibility modifications to the apartment unit and furniture were financed with a small Developmental Disabilities grant as a component of a private foundation grant. The rent for the staff apartment is paid for with UCPA privately raised funds.

Since UCPA of the Pittsburgh District has financed their apartment program two new federal benefits have become available. P.L. 94-455, the "Tax Reform Act of 1976," authorizes an income tax deduction for private businesses of up to $25,000 for the removal of architectural barriers. Thus, the owners of the apartment complex used by UCPA in Pittsburgh could have modified them to be accessible with an incentive of a tax break.

Secondly, on December 29, 1978 HUD issued final regulations establishing "independent group residences" for persons with disabilities as eligible housing for Section 8 rent subsidies. Independent group residences must house at least two occupants (in the UCPA of Pittsburgh program each apartment is shared by two persons) and can not house more than 12 disabled individuals. To be eligible, disabled residents must be in need of a planned program of daily services. Supportive services may be provided by either a resident assistant or other qualified individuals who do not reside in the group residence. The supportive service staff need not live in the residence. However, the regulation allows Section 8 rent contracts to cover the living space required by a resident assistant or assistants.

PROPOSALS BEFORE THE 96TH CONGRESS

A number of legislative proposals have been introduced in the 96th Congress (1979-1980) which would establish incentives for deinstitutionalization activities.

• Work Incentives Under SSI And DI

The House Committee on Ways and Means has reported a bill, H.R. 3236, to the House floor entitled the "Disability Insurance Amendments of 1979." In addition to attempting to save the Social Security Trust Fund money by altering the computation of benefits, the bill attempts to remove existing work disincentives in the program by (1) not counting as earnings extraordinary expenses needed to permit a severely disabled person to work, (2) extending the present 9-month trial work period to 24 months, (3) extending

Medicare coverage for 36 months to former recipients who have returned to work, (4) eliminating the second 24 month waiting period for Medicare if an individual cannot sustain work and returns to disability insurance, and (5) authorizing DHEW to develop experimental demonstrations by encouraging work for disabled beneficiaries.

The Ways and Means Committee has also approved H.R. 3464 which would promote work incentives in the Supplemental Security Income (SSI) program. The bill would increase the amount of earnings that an individual can have and still be considered to be disabled; it would increase the substantial gainful activity (SGA) earnings level. SGA would be increased from $280.00 a month to $487 a month, bringing the disabled up to parity with the blind and elderly. Additionally, certain impairment related expenses, including attendant care, would be discounted in computing income.

H.R. 3464 makes two other changes with regard to the treatment of an individual who reapplies for SSI. First, an individual who reapplies within 4 years would be considered presumptively disabled. Second, an individual would be deemed disabled for 15 months after completing a trial work period and benefits were terminated because of continued work in SGA.

H.R. 3464 also provides for continuation of SSI benefits to a disabled individual during the period when the individual is participating in an approved vocational rehabilitation program under a state VR plan.

On the Senate side two bills have been introduced expanding SSI benefits. S. 591, by Senator Robert Dole (KS), is similar to the basic thrust of H.R. 3464. S. 603, by Senator Jacob Javits (NY), would allow disabled SSI recipients to remain eligible for Medicaid if they are determined to be medically disabled, despite earnings over the present or proposed SGA level.

• Social Services Support

H.R. 3434, reported from the Subcommittee on Public Assistance and Unemployment Compensation to the House Ways and Means Committee, would increase the permanent annual ceiling to $3.1 billion for F.Y. 1980 (the 1979 level is $2.9 billion, up from $2.5 billion in 1978). The bill would place a cap on social services training funds at 3% of a state's regular Title XX allotment with a requirement that beginning in 1981 states submit an approved plan to DHEW. The Administration is supporting an amendment that Title XX be viewed as a last dollar program rather than a first dollar program. Private non-profit organizations, such as UCPA, are advocating an amendment to eliminate all statutory limitations on the use of privately donated funds as a state's matching.

• National Health Insurance Proposals

In late March, 1979 DHEW Secretary Califano announced the principles of an Administration National Health Insurance proposal. No details were announced other than this is "Phase I" of a proposal. The proposal appears to combine a catastrophic health insurance program with reforms in Medicare and Medicaid. It is difficult to determine from press releases and oral Congressional testimony the specific Administration proposals.

The current emphasis within the Congress is on a catastrophic illness protection schema. S. 350, by Senators Russell Long (LA), Abraham Ribicoff

(CT), and Herman Talmadge (GA) and six others, would establish a catastrophic health insurance plan, standardize and federalize the Medicaid program, and promote standardization of private health insurance plans. The thrust of S. 350's catastrophic protection is to cover financial burdens for traditional medical services after an individual has incurred a medical bill of $2,000 or spent 60 days in a hospital during a calendar year. Senators Long, Talmadge, and 9 others have also introduced S. 351 which is identical to S. 350 except for the absence of the Medicaid revision. Senator Long has also modified S. 350 with S. 760; benefits are similar but the financing mechanism differs.

The Republican alternative to S. 350 and S. 351 is S. 748, by Senators Robert Dole (KS), Peter Domenici (NM), and John Danforth (MO), which would expand the range of Medicare benefits and numbers of recipients including the addition of catastrophic coverage, require employers to offer a catastrophic health insurance plan to full-time workers, and authorize the federal government to negotiate between insurance companies and uninsured persons in contracting for catastrophic coverage.

• A Word On Appropriations

The fundamental Congressional issue related to human services delivery in the 96th Congress will be annual appropriations levels. These decisions will largely determine the impact of the 95th Congress initiatives. This paper will not review these issues; readers should refer to the February, 1979 Word From Washington for baseline information and subsequent issues for descriptions of the legislative consideration and decisions regarding these proposals.

ADVANTAGES AND DISADVANTAGES OF ICF/MR FUNDING FOR SMALL GROUP RESIDENCES

(Sources: National Association of Private Residential Facilities for the Mentally Retarded. Links. Falls Church, VA: NAPRFMR, March, 1979. Pages 4 and 6-7 and S. 505, "Medicare/Medicaid Administrative and Reimbursement Reform Act of 1979.")

• Overview

Since 1971 the legal authority has existed for Medicaid to finance Intermediate Care Facilities for the Mentally Retarded (ICF/MR) and persons with "related conditions" defined as persons with developmental disabilities. Because there is currently no federal ceiling on Medicaid funding, because the federal matching is very reasonable, and because of severe funding limitations within all federally financed service programs, several states have financed small group residences for the developmentally disabled as ICF/MRs.

For example, in Minnesota there are 20 group homes for the mentally retarded for 6 to 10 persons financed as ICF/MRs. The population served in these community-based facilities is similar to those people who remain in the state institutions. Additionally, 250 private community-based programs for the mentally retarded are certified as Medicaid facilities.

There have been reservations expressed by program staff associated with consumer organizations, such as the National Association for Retarded Citizens

and UCPA, about the desirability of promoting on a large scale group living arrangements financed completely by the ICF/MR authority.

• Advantages

Those that advocate ICF/MR utilization expansion emphasize several points. One, Medicaid appears to be the most easily available funding resource for residential programs. Two, the states are permitted much flexibility in interpreting Medicaid regulations. Three, the ICF/MR program need not perpetuate the medical model. For example, the requirements for "qualified mental retardation professionals" include backgrounds in the social sciences and education and not necessarily medical or nursing experience.

• Disadvantages

Those who express reservations about promoting ICF/MR funding (no one is totally opposed to developing ICF/MRs for certain persons) emphasize other points of view. One, they mainatin that there exists a medical orientation in the ICF/MR program; the authority is contained in the Title XIX "medical services" program. They raise questions such as: Does it maximize independent development? Is programmatic appropriateness determined by funding convenience? Do all residents of ICF/MRs require 24 hour supervision? Two, keeping the Title XX precedent in mind, there is a possibility for Congress to place an abritrary ceiling on Medicaid's open-endedness. The current Congressional concern with cost-containment reflects this concern. Three, many feel that there are added costs attached to ICF/MR construction. Is it not difficult to avoid an institutional orientation because of licensing and fire safety requirements? It generally takes 2 years to develop and construct an ICF/MR; when compared to utilization of existing housing, should deinstitutionalization be held up this long?

Four, the flexibility granted to the states can be a real problem. In Colorado, anyone admitted to a Title XIX facility is required to remain there for a minimum of one year. Five, there is a tendency in ICF/MRs to associate individuals by commonality of classification whether by diagnosis or function; is this normative? Six, does the federal government have the ability to do a good job of monitoring?

And last, there is the possibility of Congressional restrictions on the use of Medicaid for small group residences, particularly non-medical ones. Under existing law, State Medicaid agencies decide if ICF's are qualified to participate in Title XIX. S. 505 would establish a uniform health care facility certification process for Medicaid and Medicare long-term care facilities. State agencies would continue to survey facilities but HEW would determine a facility's eligibility.

This debate revolves around the honesty of planners, administrators, advocates, consumers, and policy makers in balancing programmatic philosophy and objectives with funding availability. Good intentions and basic value orientations are fundamental to the debate.

NARC-PVA FEDERALIZED HEALTH CARE SUPPORT PROPOSAL

In March, 1979, Elizabeth Boggs, Ph.D., and Myrl Weinberg of the National Association for Retarded Citizens and Lynn Phillips of the Paralyzed Veterans of

America drafted a "Federalized Health Care Support Proposal." It is the intent of NARC and PVA to build a broad based coalition to work with Congress in encouraging adoption of the proposal; UCPA has endorsed the proposal and expressed its willingness to work for its adoption.

The objective of the proposal is to extend reliable health care coverage to persons who have qualified as disabled under Title II (Disability Insurance) and Title XVI (Supplemental Security Income) of the Social Security Act. The proposal is intended to provide incentives for employment for those under age 65 and promote independent community-based living by allowing those whose need for health-related care can be appropriately met in non-institutional settings to receive such services. The proposal is intended to strengthen the interaction between SSI, DI, Medicare, and Medicaid.

- Problems Being Addressed

(1) The Concept Of Substantial Gainful Activity

Under present law health care coverage ceases, along with cash benefits, if the disabled person begins earning more than $280 a month (which is "substantial gainful activity") even though the individual's physical or mental impairment remains severe.

The proposal declares that "the arbitrary 'substantial gainful activity' test (which disqualifies, as 'not disabled,' anyone who manages to earn more than about 60% of the federal minimum wage) is unacceptable, and will remain the primary work disincentive for the majority of beneficiary candidates whose realistic aspirations could lie in unskilled work or part time work or work in the secondary job market with minimal fringe benefits."

(2) Unavailability Of Health Care Coverage In The Private Sector

Studies have demonstrated that a person with a pre-existing chronic condition finds it extremely difficult to obtain a policy of any kind and especially one covering needs other than short term hospitalization.

(3) Disincentives For Non-Institutional Alternatives

Medicare and Medicaid is currently structured to make it much easier to obtain in-patient services in a medical facility rather than in a noninstitutional setting.

(4) Lack Of Work Incentives For Persons In Institutions

The proposal states that "although options to do so are technically open to the state, the slant of federal policy is to require 100% of earnings (even though they may be "insubstantial") to be applied to the cost of care" for persons residing in Medicaid financed facilities.

(5) Inequitable And Unreliable Health Coverage Of Federal SSI Beneficiaries

Ambulatory health care benefits are left open to state option

under the Medicaid program. Additionally, the proposal states that "eligibility structure for the state-operated Medicaid program restricts the right of those states which might have the wisdom to do so to provide meaningful coverage for disabled persons not on SSI under state Medicaid programs for the medically needy."

- A New Modified Medicare Benefit For Persons With Long-Term Disabilities

The NARC/PVA proposal is a departure from the present method of classifying disabled individuals as either totally entitled or totally ineligible based upon the ability to enter the labor market at some point. The proposal recognizes the need for an integrated federalized health care support system for the disabled who are already within the federal programs. This proposal is a logical expansion of the SSI concept which placed a uniform floor of support under all low income disabled persons.

(1) Expanded Medicare Coverage

The NARC/PVA proposal would extend Medicare coverage to two additional groups of people not now eligible. One group are SSI disabled beneficiaries who have been disabled 29 months or more and do not have a DI entitlement. The second group are former beneficiaries under DI or SSI who meet the medical criteria or equivalent for disability and who have been disabled at least 29 months but who have had benefits suspended because earnings are "substantial."

The 29 months period is the current Medicare waiting period; 5 month wait for benefit eligibility plus 2 year waiting period for Medicare.

(2) Recognition Of Specific Health Care Needs Of The Disabled Under Medicare

Both Medicare and Medicaid were designed for purposes other than the health care needs of the disabled. For example, currently emphasis is on pre-hospitalization or skilled nursing care prerequisite before home health care services can be offered. The NARC/PVA proposal suggests the following specific modifications to Medicare benefits:

(a) Remove the requirement that home health care be predicated on the need for skilled nursing, occupational therapy, or physical therapy;

(b) Limit allowances for home health care realistically in terms of hours of care provided rather than the number of visits allowed, thus permitting some daily care;

(c) Provide for the coverage of impairment related drugs; and

(d) Provide for coverage of personal care, subject to appropriate prescription and supervision.

(3) Medicaid Options

The NARC/PVA authors anticipate savings to the states with a modified Medicare program and hope that these savings could be redirected to provide more adequate Medicaid coverage for all low income disabled persons. Anticipated Medicaid options advocated include:

(a) Full Medicaid coverage to all SSI recipients during the first 29 months after onset of disability;

(b) Medicaid coverage of premiums, deductibles, and co-insurance for those receiving the modified Medicare benefits; and

(c) Continuation of long-term in-patient services.

(4) Revised Definition Of Medical Indigency

Section 1903(f)(i) of the Social Security Act defines the "medically indigent" as persons whose incomes are no higher than 133% of the state's Aid To Families With Dependent Children standards. The NARC/PVA proposal recommends revising this definition to allow eligibility up to 133% of the SSI income level.

CONCLUSION

This paper has reviewed a variety of alternative proposals for increasing federal resources devoted to deinstitutionalization. It is important that members of the Congress become aware of the nature of deinstitutionalization activities. Specifically, they need to know about community program ideas and the inadequacy of existing financing schemes and they need to be reminded of the litany of studies and recommendations made over the past two years. Despite the Proposition 13 mentality, if the deinstitutionalization momentum is to continue, changes in existing programs must be made accompanied by increased annual appropriations. Without these statutory changes and added dollars, the federal system will continue to promote institutional care, some of which is inappropriate and inadequate in terms of quality.

UCPA affiliates are encouraged to communicate with the UCPA Washington office to develop strategies with their members of Congress in seeking statutory changes and increased appropriations.

United Cerebral Palsy Associations Inc.

Chester Arthur Building
425 I Street
Northwest
Suite 141
Washington,
D.C. 20001